

# Enforced death: enforced life

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## Author's abstract

*The notion of 'quality of life' frequently features in discussions about how it is appropriate to treat folk at the beginning and at the end of life. It is argued that there is a disjunction between its use in these two areas (1).*

*In the case of disabled babies at the very beginning of life, 'quality of life' considerations are frequently used to justify enforced death on the basis that the babies in question would be better off dead. At times, babies with severe disabilities are thus allowed to die or even killed. In the case of terminally ill people 'quality of life' is also important in guiding the actions of doctors. However, in the case of individuals who do not wish to live any longer because their quality of life is so poor that they would rather be dead, quality of life is likely to be dropped as a guiding principle. Thus patients who wish to die and ask to be killed, will most often be forced to endure enforced life.*

The slippery concept 'quality of life' has become a very common part of the linguistic practice of those who are concerned with medicine as clinicians or as professionals in related areas such as medical ethics and health economics. As a result it has gained an aura of respectability almost as if it were a clinical or scientific expression, and almost as if there was some way of measuring it.

'Quality of life' frequently figures in discussions about life and death. At the beginning of life, for example, it may be argued that a life is likely to be of such poor quality that it can be justifiable (even merciful) to deny its bearer treatment and/or sustenance that will prolong it. I propose to contrast the importance frequently attached to speculative estimates about quality of life in such situations, with the way in which assessments of quality of life may be laid to one side in the case of terminally ill patients who would rather die than live with the poor quality of life they are experiencing.

## i. The beginning of life

References are often made to 'quality of life' in

arguments about whether abortion can be right, at least in the case of babies who are known to be disabled to some degree, and also in arguments about whether it can be right to withhold treatment or even food, from newly born infants with disabilities. This use of the notion of quality of life constitutes a danger for babies who do not match up to society's norms of perfection.

The argument often goes something like this: 'Since this baby would have such a poor quality of life it would be better off dead'. The cases most likely to come to public attention are those involving babies with spina bifida and babies with Down's syndrome. References to 'quality of life' in deciding on courses of action in such cases are often illicit. By this I mean that the notion is often used to justify decisions by making them look as if they are about the quality of life of the baby when really they are about the quality of life of someone else.

Killing a baby or allowing her to die necessarily involves acting without taking into account her views about whether her quality of life is such that she wishes to live the life she has. Of course it would not be possible to ask a newly born, or yet to be born, baby whether she wanted to live the life she had. There are, however, a variety of things that could be done:

a. **Firstly**, the current situation where doctors make more or less informed guesses, on the basis of clinical experience, about the quality of life of disabled people, could be formalised by asking people with disabilities whether they would rather be dead than live with the handicaps they are living with. Such information could then be extrapolated to the lives of babies; those suffering from a degree of disability that adults commonly insist makes their lives such that they wish they had never lived, could be killed. This possibility would have some similarity to the way in which QALYs are calculated and shares with them the disadvantage that different people with the same disability will experience that disability as more or less of a handicap and as more or less detrimental to their quality of life. Though we might be able to guess at the level of physical pain or of mental disability which an individual would experience, the 'quality of life' that she will experience is not open to measurement. 'Quality of life' is a subjective notion. I cannot tell what

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your quality of life is, you cannot tell what my 'quality of life' is and neither of us can say what the quality of life experienced by a disabled baby will be.

**b. An alternative** would be for doctors to wait until the disabled person was able to express her own preference. If she turned out to be severely disabled, such that others found it hard to believe that life for her could be tolerable, she could be asked whether she wished to live with the quality of life she had at that point. If she expressed what seemed to be a rational preference to be dead she could then be killed or assisted in killing herself. This would require a commitment to the notion that at least some people who wish not to live, have the right to be killed or helped to die. As I make clear when I come to talk, later in this paper, about requested euthanasia, I believe that at least some people do have such a right. However, I am unclear about what conditions would have to be fulfilled before a person should be able to expect that others would help her to die.

The charge might be made that this possibility is rather ghoulish; on the face of it I can understand this charge: it is difficult to imagine allowing (some might say *forcing*) a person to live until she could be asked whether she wished to be killed, and the idea of killing those who respond positively to the question of whether they wish to die is quite shocking. On the other hand, the idea of killing disabled people who say that they would like to be killed seems to me to be a good deal less horrific than killing them or allowing them to die before they are able to express any opinion about whether they would like to live or die.

The reason this proposed possibility is likely to be thought shocking is, I think, related to the ways in which, as a society, we think about babies. The idea of killing people who have grown past the stage of babyhood and ask to be killed sounds horrific because they are likely to look like us, and others are likely to have formed relationships with them. It will be harder to do the deed. On the other hand, little babies have not yet formed real relationships with others and they look a bit different so that it is possible almost to imagine that they are not yet people—at least not real people like us. When they are inside the womb, this is even easier; hence the greater acceptability of abortion over infanticide, whether active or passive.

**c. A third and better, alternative**, would be for doctors to wait until the person herself let them know that she was unhappy with life and wished to die; thereafter they would proceed as in the previous alternative: if her preference was considered to have been autonomously made, she would be helped to die or killed. This alternative would have the benefit over the last, that doctors would not put (and could not be accused of putting) ideas into the heads of those who were satisfied with their lives or at any rate would rather put up with them than die.

The second and third alternatives share a problem: the possibility that some babies would be condemned to

live lives that they would rather not live, until they were considered able to opt out. However, I do not think this would be any worse than allowing to die, or killing, those babies who, had they lived, would have been glad to be alive (2).

I have suggested three strategies that could be adopted instead of allowing babies with disabilities to die or killing them because we guess they will have a poor quality of life. We could ask older people with similar disabilities about the quality of life they are experiencing and extrapolate this information to our considerations of disabled babies; we could wait until they are able to share information about how they are experiencing the lives they are leading when asked to do so; better still, we could wait until they approach those with the power of life and death to inform them that they do not wish to live any longer. All three of these strategies share the disadvantage that they could not take account of the views of people who were so disabled as to be incapable of expressing, perhaps even formulating, any view on the quality of their lives. But this is no worse than the current practice of aborting disabled babies or allowing them to die after birth without any indication of their preferences in the matter, because this cannot take account of their views either.

What I have said so far may seem simplistic because I haven't taken account of the very wide range of disabilities with which a baby can be born. Whereas some disabled babies will have disabilities of a very minor kind, many will be seriously handicapped by their disabilities and some will be so severely disabled that they are unlikely ever to experience life in any sense that we can relate to. In at least some cases of the latter kind I think it might be possible to make out an argument on utilitarian grounds, to justify their deaths; this could be done in relation to either infanticide or abortion though I think it would be easier to justify the former than the latter because greater certainty about the child's condition is possible after birth than before. Such a case might, for example, be made out in relation to anencephalic babies on the basis, not that they would have a poor quality of life, but on the basis that they could not have lives of any kind and that therefore it would be wrong to use resources to keep them alive that could be used to save or enhance the lives of others, perhaps other severely disabled infants, who *do* have lives. However, though such a case could probably be coherently made, it clearly brings with it some moral dangers. For example, if such an argument was accepted it could be extended both to older people with similar disabilities and to babies whose disabilities were much less extreme.

Another utilitarian argument that might be made would create similar dangers. This would be the argument that the lives of at least the most severely handicapped infants should be ended on the grounds that they are likely to require so much money spent on them that others, including other severely but less

drastically disabled infants, will suffer as a result; the danger in this case is that the argument could be modified to apply to any individual whose condition was such that she was likely to require sustained and expensive medical treatment.

An easier case could be made out in relation to the allowing to die, or killing, of babies who, because of gross abnormality or genetic disorder were unable to live for more than a very short period of time and were likely during that time to suffer greatly. Again I will not enter into this here except to say that the argument would hinge on the amount of suffering caused to such a child during a short and fruitless existence. I have lived for many years with the feeling that rather than allowing my own baby to die in the way that she did die, it might have been better to kill her (3). In at least some such cases I think it might even be argued that it was morally wrong not to bring death to the baby.

So I have suggested that sometimes allowing babies to die or killing them, may be morally justified or even morally required. But I think it will rarely be possible to justify this by referring to the quality of life of the baby concerned.

Sometimes references made to the 'quality of life' of a baby may be made to justify actions that in truth are intended to protect the quality of life of their families or of society. Many people who could have had lives that they would have wished to lead had they been allowed to do so, are thus killed or allowed to die. As an example of the kind of person I'm talking about, let me quote a letter to this journal from a young woman who believes she could well have ended up dead on the basis that the quality of the life she was destined to lead was likely to be low (4).

'SIR

In reference to your items on the bill drafted by Mr and Mrs Brahams permitting doctors to withhold treatment from newborn handicapped babies, I would like to make the following points.

I am 28 years old, and suffer from a severe physical disability which is irreversible, as defined by the bill, I was born with myelomeningocele spina bifida. Mr and Mrs Brahams suggest several criteria for predicting the potential quality of life of people like me, and I note that I fail to fulfil most of them.

I have suffered considerable and prolonged pain from time to time, and have undergone over 20 operations, thus far, some of them essential to save my life. Even now my health is at best uncertain. I am doubly incontinent and confined to a wheelchair and thus, according to the bill, I should have 'no worthwhile quality of life'.

However, because I was fortunately born in rather more tolerant times, I was given the chance to defy the odds and live, which is now being denied to handicapped newborns. Even so, my parents were encouraged to leave me in the hospital and 'go home and have another' and I owe my life to the fact that they refused to accept the advice of the experts.

Despite my disability I went to an ordinary school and then to university, where I gained an honours degree in sociology. I now work full-time defending the right to life of handicapped people. I have been married eight years to an able-bodied man, and over the years we have travelled widely in Europe, the Soviet Union and the United States. This year we plan to visit the Far East.

Who could say that I have "no worthwhile quality of life"?

In writing this letter, Alison Davis was referring to the draft bill on the treatment of chronically disabled infants drawn up by Diana and Malcolm Brahams, respectively a barrister and solicitor, and published in the *Journal of Medical Ethics* in the same year (5). A consideration of their proposed bill offers some support for my contention that 'quality of life' may be used in relation to babies when in fact it is the quality of life of others that is being considered. Such a bill, had it become law, would have made it permissible to fail to treat a very young patient if certain conditions about the baby's quality of life were fulfilled, specifically if his or her disability was:

'... of such gravity that the patient (after receiving all reasonable treatment) would enjoy no worthwhile quality of life.'

In expanding on what they meant by this the Brahams went on to talk about aspects of the baby's life such as '... the degree of suffering (both mental and physical)' it is likely to suffer. They referred further, in 3) (ii) to:

'the ability and willingness of the parents of the patient to provide the care and facilities appropriate to the patient's condition'.

and in 3) (iii) to:

'the likely effect on the mental and physical health of the parents and other members of the patient's family of the need to provide such care and facilities to the patient during his probable lifetime'.

Note that 3) (ii) and (iii) have nothing at all directly to do with the quality of life of the patient and everything to do with the quality of life of the family.

Now in most circumstances it does not seem to me to be a sufficiently good reason for allowing a baby to die, to argue that if she lives the quality of life of others will suffer. However, more than anything else what is objectionable here, is that references are being made to the quality of life of the baby when that quality of life is being defined, at least partly, in terms of the quality of life of others.

So I've argued that the justification of the allowing to die or killing of disabled infants and babies on the grounds that their quality of life is likely to be so bad that they are better off dead than alive is most often

inadequate and at least sometimes, dishonest.

## ii. The end of life

Let me turn now to the consideration of 'quality of life' in terminal care.

Some time ago I attended a meeting at which a very committed and experienced doctor spoke about her work in a hospice. She also spoke about euthanasia. She believed that whereas it was right to help dying people to enjoy the life left to them in the best way possible, it could never be right to kill them. She believed that her work in the hospice increased the quality of people's lives, sometimes dramatically, in their last days and weeks and months and she illustrated this by reference to cases she had worked with.

This dedicated doctor's entirely laudable aim was to help her patients to live with the best possible quality of life until they died and to this extent her account of her actions demonstrated the importance she laid on quality of life. She was sincere and passionate in her caring. However, much though I admire her dedication and skill in the use of drugs in giving people the best possible quality of life until they die, there is a sense in which it seems to me that she was willing to abandon her commitment to 'quality of life' because her commitment to the absolute rule against killing was even stronger. Thus even in circumstances where a patient's quality of life had dropped to the point at which he, the patient, would rather die than live, and had asked to be helped to die, she said she would be unwilling even to contemplate killing him. This was so even in cases in which her considerable skills in pain control could provide no more aid. To refuse to help such a patient to die seems to me to fail to treat quality of life as important.

Of course, this position is not unusual. Many if not *most* doctors in this country would refuse to contemplate killing, even those who are willing to prescribe sufficiently large dosages of drugs to guarantee the death of the patient, in order to relieve their pain, and those who are willing to 'allow patients to die' when they judge that it would be in their best interests to die. For such doctors the refusal to contemplate euthanasia depends in part, upon self-deception because it involves deceiving themselves into believing that allowing people to die is less morally significant than killing; and it seems to me to be perfectly clear that the moral importance of these actions depends upon the circumstances in which they take place rather than on the fact that one is active while the other is passive. As John Harris has written, in relation to the selective non-treatment of severely handicapped infants, '... non-treatment is a death-dealing device' (6).

It strikes me as odd that doctors who believe quality of life is important should deny death when the quality of life a person is experiencing is so bad that she sees death as an advantage and there is no prospect of things changing so that her quality of life will improve. One

reason for this I guess, is that they cannot imagine themselves being the kind of person who would actually kill a patient, because they see their role as being about preserving life. However, while the preservation of life seems to be a thoroughly laudable aim, I do not believe it should be pursued at the expense of the quality of life of the patients whose lives are in question. It is interesting to recall that as discussed in the first part of this paper, doctors who believe in allowing severely disabled infants to die, clearly do not believe at least in relation to very young people, that there is an imperative in favour of preserving life at all costs, even at the cost of quality. Indeed it is precisely the speculated quality of life faced by such infants that they use to support their decisions in favour of, for example, 'non-treatment'.

On the face of it, doctors who refuse to kill their patients seem to be making a bid for the moral high ground. Doctors, in general should not kill. However, adherence to an immovable belief in the sanctity of life, to the idea that doctors must never kill their patients, carries moral dangers. Those doctors who share the view that killing must never be allowed even in the case of terminally ill patients who have rationally asked to be killed, must be willing to commit such patients to lives of pain so great that they would rather be dead than live with them. In a sense doctors who act thus are guarding their own quality of life at the patient's expense, in that they are guarding their personal integrity as people who do not kill. This would be rather like the position in Bernard Williams's example of Jim and Pedro, if Jim refused to kill one person to save the lives of nineteen even though the one he could have killed was bound to die anyway (7). Jim, a nice young Englishman exploring in the South American jungle, stumbles upon Pedro, who is about to have twenty innocent natives shot. After Jim objects Pedro offers him the opportunity to save nineteen of the natives by killing one himself. Now if Jim refused to kill the one in order to protect his own integrity that would seem wrong because as a result nineteen people would die who could have been saved. In a similar way it seems to me that doctors who refuse, even in circumstances such as I have described, to kill their patients, do so to protect their own integrity and as a result allow patients who could have died comfortably and in their own chosen time, to die less good deaths than they could have done.

## Possible misconceptions of, and objections to, my position

I should attempt to deal with some ways in which my position could be misconstrued and with some possible objections to it.

i. Firstly, let me be clear about the extent of support that I am giving to those who advocate euthanasia in its various forms.

I strongly support the idea that euthanasia, when it is requested by those who are terminally ill and in great

pain or distress, is morally justified. However, I am aware that there may be difficulties in telling whether a person who asks to die really wants death rather than a rest from intolerable pain or distress for a time. For example, I am aware that there are times in terminal illness when a patient in great pain may say that she wishes to die, when doctors know from experience that given a few days she will change her mind and be glad to find herself alive. I do not mean to suggest that patients in such a period of depression should be killed even if they ask to be killed. My contention is simply that if occasions arise when doctors believe they can do nothing further for their patients short of rendering them unconscious or non-autonomous, they would be morally right to kill them if their patients asked rationally for death at that time.

I am not supporting non-voluntary or involuntary euthanasia. Nor am I suggesting that whenever a patient thinks her life isn't worth living any longer and asks to be killed, that her doctor should kill her; to say this would be to suggest that anyone who is depressed with life has the right to be killed and I certainly don't believe that.

ii. Secondly, there may be a misconception about who I think should be expected to kill patients who request euthanasia in circumstances such as I have suggested would make killing a justifiable option.

Throughout the paper I refer to 'doctors' as if they are the only people who are involved in making decisions about the lives and deaths of babies and terminally ill patients. This does not mean I think they are the only people involved or who should be involved; nor indeed does it mean I believe there is any necessity that they are the ones who should be involved, in arranging for the deaths of those who are to die. Nothing about my argument would change if 'nurses', 'close relations', 'close friends' or 'parents' were substituted for 'doctors' as appropriate, provided they had the required knowledge of the patient's condition and the ability to assist the patient to die. In particular I do not intend, in referring to 'doctors', to give the impression that doctors are the only people upon whom the responsibility should fall to help others to die in circumstances such as I describe; anyone asked for help in dying by a terminally ill patient, with the necessary knowledge and skill, would occupy the moral space I suggest doctors do, in these circumstances. However, I find Roger Crisp's argument for a new medical specialty, to be called 'telostrics', in which doctors would specialise in a mixture of hospice care and euthanasia, an interesting solution to the problem caused by deciding who should help people to die by euthanasia and perhaps such doctors would indeed be best situated to bring death to those who want it (8).

So far as objections to my arguments go:

i. Firstly, it might be objected that my case is

misplaced because there never are situations in which pain cannot be controlled even in cases, say, of cancer involving the nervous system. I have found it difficult to get this straightened out with medical and nursing colleagues who seem to have different opinions about whether such pain ever occurs. However, my argument would be the same even in cases where it was possible to control pain where that pain is such that in order to control it a patient would have to be given such high dosages of drugs that she would be likely either to lose consciousness or lose her autonomy in the sense of becoming less able to think straight. In such circumstances I think that before the drug is administered such a consequence should be made clear and I think this would certainly be the kind of case where it would be right to respond positively to a request to die if the patient preferred this to ending up in such a state. My case would also remain the same if the reason that a patient considered her life was such that she would rather be dead rested, not upon the amount of pain she was experiencing, but on the amount of distress caused by irremediable symptoms such as nausea, constipation and hair loss which might be associated with chemotherapy; or by incontinence and bleeding from nose and mouth which may accompany conditions such as lung cancer.

ii. Secondly, it might be objected that my proposals do not allow for the difference in expertise between doctors working within hospitals and those working within the hospice movement. A problem for my position, it would be claimed, arises since most doctors who do not work in the hospice movement have much less experience and expertise in the control of pain, than those within the movement, for whom it is a specialty. This means that patients in painful terminal conditions in hospital might want to die under circumstances such as I have argued would justify euthanasia, when had they been in a hospice, it might yet have been possible to do something further for them. Among other things this means we should push for hospice-type provision to be made available within all hospitals where patients might have to suffer until they die. It also means, however, that I feel compelled to support the requested euthanasia of those individuals where it is not possible to transfer them to a hospice; the fact that at another time or in another place, they might have been helped, is no reason for depriving them of the help we could give them now, even when that help involves killing them at their request.

## Conclusion

From what I have said thus far I hope it is clear that there is an inconsistency in the way in which the concept of 'quality of life' is used at the beginning and at the end of life and further that this inconsistency is likely to lead to harm for two groups of people, one large and one small. The large group is made up of those babies born, or unborn, who suffer, or seem

likely to suffer, from disabilities so severe that others judge that their lives will be of such poor quality as to make them not worth living. The smaller group is made up of those who are suffering from terminal conditions so severe that they themselves judge their lives to be worth living no longer.

The harm that may be done to disabled babies will come about because at the beginning of life quality is likely to be treated as so important that the absence of certain features thought by some people to be necessary before an individual can have a worthwhile quality of life, may be used to justify enforced death whether by abortion or 'allowing to die' after birth. The harm that is likely to be done to terminally ill people who wish to die, will come about because although quality of life is considered important, at times when it comes to life-and-death decisions it is overlooked because the imperative against killing seems to be regarded as stronger than the imperative against bringing about suffering; dying patients may thus be made to suffer enforced life.

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## References and notes

- (1) I am grateful for helpful comments on earlier drafts of this paper to Susan Fairbairn, Heather Draper and John Harris. I am grateful also to Raanan Gillon and the anonymous referees who pointed out some of the weaknesses of the paper in an effort to help me to be more coherent. None of these people agrees with my position as I have expressed it here.
  - (2) Undoubtedly there are many cases in which this is true even though, of course, there is no empirical way of proving it. On the other hand reference to the experiences of other individuals, equally disabled in an objective sense gives some credibility to this claim (see for example Alison Davis's letter cited in this paper).
  - (3) My daughter suffered from a rare genetic disorder that meant she could not survive. I discuss some other events surrounding her death in Fairbairn G J. When a baby dies – a father's view. *Nursing practice* 1987; 1: 167–168.
  - (4) Davis A. Right to life of handicapped [letter]. *Journal of medical ethics* 1983; 9: 181.
  - (5) Brahams D, Brahams M. The Arthur case – a proposal for legislation. *Journal of medical ethics* 1983; 9: 12–16.
  - (6) Harris J. *The value of life*. London: Routledge and Kegan Paul, 1985: 34.
  - (7) Williams B. A Critique of Utilitarianism. In: Smart J C C, Williams B, eds. *Utilitarianism: for and against*. Cambridge: Cambridge University Press, 1973: 97.
  - (8) Crisp R. A good death: who best to bring it? *Bioethics* 1987; 1: 74–79.
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